

Summer Directive 2022

Part 1: Grudging acts

In this Directive, we are interested to hear about your thoughts and experiences of grudging acts. These are the things we do (or fail to do) not because we want to do them, but because we feel that we must. They are the things we do with reluctance, or they can be the things we fail to do, when we bite our tongue, or exercise avoidance and self-restraint.

You may have undertaken grudging acts in a variety of settings: for family and friends, in your leisure activities or at work. You may also have undertaken grudging acts for a variety of reasons: for example, because you felt a sense of obligation or moral responsibility; because it helped you to do something that you did value; because you feared how others might react; or because taking part was easier than swimming against the tide.

We are interested in hearing about the different types of grudging acts you have engaged in and why you felt you had to do them.

Please do not feel that you are tied to the questions – feel free to respond in any manner you feel is best.

Your own experiences

To start could you describe some of the grudging acts you felt you had to undertake? These could be things you felt you had to do, as well as the things you felt you couldn't do (such as speaking up or objecting).

Please share any examples of particular relationships or settings where you were obliged to participate grudgingly? These could include grudging acts for friends or family, in your leisure activities, at work, or for bureaucracies/ government.

Were these acts grudging from the outset or something that became increasingly grudging over time?

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Remember *not to identify yourself or other people inadvertently within your reply. It is best to use initials instead of real names.*

Why you participated

What made you participate in these grudging acts? Was it a sense of obligation, or it made your life easier, because you felt it was the right thing to do, or because you were worried about the consequences?

How did it make you feel? Did you feel frustrated, disillusioned, or irritated, or did you think it was a necessary part of some broader purpose?

Grudging acts during Covid-19

The changing restrictions imposed during Covid-19 caused many disruptions to our everyday lives. These disruptions might have created new grudging acts but could also have allowed you to escape older grudging practices.

Were there any grudging activities that Covid-19 restrictions allowed you to suspend or evade? Did the changes in your everyday life make you think differently about some of your old activities and realise that they were grudging?

Could you describe some of the grudging acts that you felt you had to undertake during the restrictions? Why it grudging and why did you feel you had to comply? Was your feeling of grudgingness affected by how other people followed (or not) the new rules?

Part: 2 Genetics and health in our everyday lives

For this Directive we are interested in your views and experiences of genetics and health.

Genetic tests are being used more and more ... from ancestry genetic tests that link long-lost relatives to plans to screen new-born babies with DNA tests.

20 years ago, genetic tests could only examine small portions of the genetic code, and this was technically difficult. Now tests can sequence a person's entire genetic code (genome) quickly and cheaply. Sometimes this helps to diagnose a condition, or determine a

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treatment, but other times we don't know what to do with the information found through such tests.

Developments in genetics mean that medicine can sometimes be made more personalised to an individual, rather than a whole population.

Your experiences of healthcare

Thinking about your own experiences of healthcare (this does not need to include genetic testing):

- Can you describe a time when you felt you **experienced care that was personalised** or tailored to your own specific situation?
- We would also like to hear about experiences of care that **did not** feel personalised to your own circumstances.
- Have you ever felt that any aspects of your identity or background have affected your experience of healthcare?
- On what basis do you think medical care should (or should not) be tailored to you? Please share your feelings on this.

Genetics in our everyday lives

Please share what comes to mind when you think of 'genetics'. You are welcome to write down words, phrases, or to include images or sketches.

Please tell us about **any experience you have had of genetic testing** including the experiences of those around you – family, friends, neighbours, colleagues, and others. You could include any test that has looked at your DNA (genetic code) either via the NHS or those bought direct from shops/online (e.g. Ancestry tests or 23andMe).

Are there any news reports, films, television programmes or books about genetics that have been of interest to you? If so, please share how or why.

The issues genetic testing can raise

We would like to hear your thoughts on the following fictional scenario:

M has genetic testing after developing breast cancer. Her test finds she had a strong chance of developing breast cancer. M's doctor says that her sister could be tested for this inherited tendency (and if she has it, she could have extra screening or surgery to reduce her risks). M has not told her

sister about her breast cancer and does not want to tell her sister about the genetic result. Her sister has a 50:50 (1 in 2) chance of having a strong genetic tendency to breast cancer.

- What do you think about this?
- Do you think M's sister should be told? If so, who should tell her?
- Should M's doctor communicate the potential risks to her sister if she doesn't?
- M has agreed for her genetic data to be stored in a DNA database and used for research purposes. What do you think might be the consequences (positive or negative) of being part of a DNA database?

Future uses of genetics

How do you imagine genetics might feature in our lives in the future?

One potential future use is the UK **Newborn Genomes Programme** pilot study, which will examine the benefits and drawbacks of sequencing a baby's entire genetic code then analysing parts of it to look for various genetic conditions. It could detect more conditions than the current newborn 'heel prick' test. However, the programme might also cause more uncertainty (for example, where a possible genetic risk is found but no-one is sure if it will make the baby ill or it is unclear what the best treatment option is).

We would be interested in hearing **your views** on this initiative. What might be the potential benefits and drawbacks?

Do you have any particular hopes or worries about the future uses of genetics?

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Part 3: The Royal Family

Mass Observation has recorded people's thoughts and opinions about the royal family since its founding in 1937, when it documented King George VI Coronation with street observations and a call for diaries. When the contemporary Mass Observation Project started in 1981 it sought people's reactions to the Royal wedding of Charles and Diana.

In the third part of this Directive, we are asking you to share your thoughts and opinions on the British monarchy and its future in the Queen's Platinum year. We are keen to hear your thoughts and opinions on members of the royal family, and recent events which have drawn particular media attention such as the death of Prince Phillip, Harry and Meghan's Oprah Winfrey interview and Prince Andrew's civil sexual assault case and the subsequent removal of his royal duties. Recent Royal tours of the Duke and Duchess of Cambridge to the Caribbean and the cancelled tour of the Wessex's of Grenada have also hit the headlines.

As some countries signal their desire to leave, does the Commonwealth have a future? And finally, did you participate in any activities to celebrate the Queen's Platinum Jubilee, or did you abstain from following any of the events? Did you engage with any news and or media about the events and if so, what did you find of interest?

Please post your response to: Freepost: RTGU-AYJE-YSSC, The Mass Observation Archive, The Keep, Woollards Way, Brighton, BN1 9BP or by email to: moa@sussex.ac.uk. JS/KP Summer 2022 Directive/No. 125